



Hospital experiences of older people with intellectual disability: Responses of group home staff and family members

Journal:	<i>Journal of Intellectual & Developmental Disability</i>
Manuscript ID:	CJID-2009-0043.R1
Manuscript Type:	Research Paper
Keywords:	hospital, intellectual disability, group homes, communication



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Abstract:

Background. The study reports on hospitalization experiences of older adults with intellectual disability living in group homes.

Methods. Grounded Dimensional Analysis was used to guide data collection and analysis. Group home residents were tracked prospectively over a three year period. Interviews were conducted with family, group home and aged care staff and managers, and some residents.

Results. Findings highlighted the difficulty people with intellectual disability experience in hospital settings. Findings revealed extensive strategies undertaken by family members and group home staff to improve hospital experiences. Ageing of the family members and staffing implications for group homes complicated efforts to improve hospital experiences.

Conclusions. The current absence of systems to accommodate the special needs of people with intellectual disability in hospital settings has significant consequences for group homes, family members, hospital staff and residents. Most hospital systems appear to be poorly designed to care for this vulnerable population.

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Introduction

Rapid improvements in health care and living environments have led to dramatic improvements in life expectancy for people with intellectual disability (ID) (Janicki, Dalton, Henderson & Davidson, 1999; Yang, Rasmussen & Friedman, 2002). However, people with ID continue to experience a higher burden of illness than the general population (Beange, McElduff & Baker, 1995; Brown & Gill, 2002; Connolly, 2001; Fisher & Kettl, 2005; Janicki, Dalton, Henderson & Davidson, 1999; Walsh, Kastner & Criscione, 1997). This difference is reflected in over-representation of people

with ID in hospital settings (Janicki, Dalton, Henderson, & Davidson, 1999; Walsh, Heller, Schupf & van Schrojenstein, 2001).

Relatively negative hospital experiences of people with ID have been documented in several prior studies (Dewar, Trocher & Watson, 2003; Horwitz, Kerker, Owens, & Zigler; Iacono & Davis, 2003; Mencap, 2004; Wallace & Beange, 2008). Reported problems include: staff inattention to basic needs such as toileting and nutrition, poor communication between staff and patient, over sedation, medication errors, patient fear and anxiety, insufficient pain management and poor discharge preparation (Durvasala & Beange, 2001; Hemsley, Balandin & Togher, 2008; Ouellette-Kuntz, Gardin, Lewis, Minnes, Martin, & Holden, 2005). The role of families, particularly parents, has been prominent in the literature but the hospitalisation experiences of older people who no longer live with their parents and who live in supported accommodation or independently has not been examined (Backer, Chapman & Mitchell, 2009). Most of the studies examining hospital experiences of people with ID have reported an ongoing family presence, sometimes 24 hours/day, during hospital stays. Parents have described this vigilance as necessary to ensure adequate care, safety, and minimizing fear and anxiety (Bowers, Bigby & Webber, 2009; Hemsley, Balandin & Togher, 2008).

It is probable that younger persons with ID who are in hospital will have parents able to provide ongoing care. Older adults with ID, however, are more likely to live in community based supported accommodation and to have parents who are unavailable due to death or age-related illness (Bigby in press; Emerson, Hatton, Felce & Murphy, 2001). In the UK, for example, for people with intellectual disability under 50 years the ratio of those living in the family home to those living in supported accommodation is 70:30; by contrast, the ratio for those aged over 50 is 30:70 (Emerson, Hatton, Felce & Murphy, 2001).

This paper uses a subset of data from a larger, longitudinal study that was designed to explore the pathways into residential aged care (nursing homes) for people ageing with an intellectual disability who are living in group homes. This paper focuses on perspectives of group home staff

and family members concerning hospital experiences of group home residents, including the strategies they used to support residents while in hospital.

Methodology

Consistent with the exploratory purpose of the study, we chose a qualitative theory generating methodology, Grounded Dimensional Analysis, to conduct the study (Bowers & Schatzman, 2009.) This is a ‘second generation’ Grounded Theory methodology (Morse et al, 2009). Based on the same theoretical foundations (symbolic interaction) as other Grounded Theory methodologies, and following the same general procedures Dimensional Analysis is distinguished by the timing and sequencing of theoretical sampling and by the absence of focus on basic social processes (Glaser, 1967)

Location and Sample

The study took place in Victoria, Australia in 13 group homes, each with between 4-6 residents, which were managed by seven government or non-government disability organisations. The group home program aims to support residents to learn new skills, make choices about their life and be active in their community. Rostered staff support residents with household management, self care, personal hygiene and community participation (Department of Human Service, 2009). Most homes have sleepover staff who are available for emergencies but not generally expected to be awake during night time hours. Group home staff are not trained to care for people with serious or chronic health conditions, but have basic first aid training.

Participants included: 17 residents with ID from a group home (aged 49 to 81 at first interview) who were the focus of each cluster, in all but one case at least one family member, group home staff and, for those people who moved during the course of the study a residential aged care staff or managers plus other people who were relevant to the study. A total of 55 people were interviewed, consisting of 17 family members, 16 house supervisors, 11 accommodation program managers and 11 staff in aged care facilities. Only one person, a house manager, declined to be interviewed. This person left the organisation and the replacement house manager subsequently

agreed to be interviewed. In all, 130 interviews were conducted with between 3 and 6 people in 17 'clusters' centred round each of the 17 residents with ID.

Agencies were recruited first by telephone and, if the agency was agreeable to its staff taking part, group home supervisors were sent a letter with details of the study inviting their participation. Once staff in a group home had agreed to take part, supervisors were asked to send or make available flyers to family members of group home resident who were 45 or over. The flyers explained the study and invited family members to participate. Interested family members either contacted the recruiter directly or passed their contact details to group home supervisors to pass on to the research team. Where feasible family members discussed participation in the study with their relatives who lived in a group home but in all but one case due to their inability to provide informed consent, family member signed the consent forms. The study was approved by the Human Research Ethics Committees at the Australian Catholic University and La Trobe University.

Data collection

Data were collected and analysed by an interdisciplinary research team. The primary researchers used in person and telephone interviews to collect data. Group home supervisors and family members were interviewed separately, between two and four times over 2 ½ years. Although some people with ID (residents) were present during the interviews with family members few participated in the discussion due to the severity of their impairment, frailty or difficulty of communication. The data presented here is drawn from family members, group home (including house supervisors and program managers) or aged care staff Initial interviews were conducted in person and the two follow up interviews with non-residents by phone. In the case of residents who moved to aged care, interviews were conducted with staff and managers of residential aged care, at the time of move in and again at about six months. Although they were not asked directly about other residents, house managers also talked about other residents who had experienced health problems and how those situations had been addressed.

Following the Grounded Theory Methodology, early interviews were very non directive, asking participants to talk about ageing in a group home, what were the issues, how did ageing matter in group home life, and how they had responded to ageing of their family member or resident. During analysis we discovered that hospitalization frequently triggered a move to residential aged care. This led to a more focused data collection and analysis of hospital experiences. All accounts of hospitalization were retrospective as we did not collect data during any hospitalizations. Interviews were, transcribed and distributed to the team for analysis. Analysis was conducted on each interview prior to conducting follow up interviews. Follow up interviews were not always conducted by the same researcher. However, as the entire research team was involved in analysis of each interview, interviewers always had knowledge of past interviews.

Analysis

Analysis was done collaboratively by the research team (Caron & Bowers, 2000; Bowers & Schatzman, 2009; Strauss, 1987). In keeping with the theory-generating approach, early interviews were open and exploratory, evolving over time to facilitate axial and selective coding. For example, initial interviews were replete with references to hospital experiences and the link between hospitalization and moves to residential aged care.

Moving from open (hospitalization as significant experience) to axial coding, interview questions were adapted to explore perceptions about hospital experiences. These interview questions led to descriptions of hospital staff responses to residents, strategies used by group home staff and family members to assess and improve the quality of the hospital experience, and the consequences for residents, group home staff and family members. Theoretical sampling was facilitated through evolution of interview questions rather than selection of participants. Participants were subsequently asked to describe: a) the evidence they used to make assessments about the quality of the hospital experience, b) the strategies they used to improve the hospital experience and c) the consequences of those experiences. Selective coding led to identification of

significant conditions affecting the use of strategies, including the impact of hospital systems that acknowledged the special needs of this population.

Findings and Discussion

Twelve of the 17 residents had been hospitalised at least once during the study. An additional resident was hospitalised just prior to the study commencing and all but one of the remaining four residents had been to hospital in the last five years. The overall hospitalization rate for resident participants in this study, during a two year period was 76%. In addition to confirming prior research, this study documented the extensive strategies used by family and group home staff (carers) to improve hospital experiences for people ageing with ID. As family members and staff had consistent views and engaged in very similar strategies, they are described as a single group and referred to as carers. We are however cogniscent of the very different relationships that family members and staff had with the residents with intellectual disability.

Carers Perceptions of Hospital Experiences.

Perceptions of Hospital Staff Attitudes

Carers perceived staff to be generally uncomfortable with or indifferent to the needs of people with ID. Care practices that did not acknowledge their special needs were interpreted as indifference. “...they don’t wash them. They don’t even brush their hair or clean their teeth. They don’t put their glasses on them and they, it’s just like it’s too hard, go away” (aged care staff).

Although rarely stated directly, carers perceived that some hospital staff saw people with ID as having little value. Consequently, questions about whether a treatment should be tried were often interpreted as suggesting that the patient was not worthy of receiving additional treatment. “We had a guy here who recently broke his foot... I was told he was deemed unsuitable for rehabilitation and I mean I cringed ...that was so far below anything that was a reasonable expectation” (disability staff).

Knowledge about Intellectual Disability

Some carers interpreted staff failures as lack of caring. Others suggested that many care problems were related to hospital staff having little or no prior experience and consequently not understanding people with ID. “I don’t think they have an understanding of anything in the disability field, I don’t think they’re trained or given any information...” (disability staff).

According to carers, some hospital staff openly acknowledge their lack of skill in caring for people with ID.

... so you have the hospital throwing their arms up in the air saying that they’re not skilled to provide support for people with disability and then you have our issue with regards to not having staff skilled enough to provide the support to ageing people. (disability staff)

While some people with ID were able to care for themselves in hospital, many required support with self care tasks. Carers commented frequently about the failure of hospital routines to respond to those who needed assistance. The issues of greatest concern to family members and other members of the cluster were around eating and toileting. Carers noted that residents were often unable to access food and that hospital staff often failed to check whether meals had been eaten. Food was often left unopened and uneaten, sometimes left in the room and sometimes taken away. “When we visited him in hospital on his table was a bottle, a sandwich, unopened because he probably couldn’t do it with the one hand” (family).

Carers described people who were continent but had been diapered rather than being taken to the toilet. Most often this was attributed to the inability of residents to ask to be taken to the toilet and the failure of staff to anticipate their needs. “...and the staff there had him in continence pads the entire time even though he’s continent and they were too busy so they just stuck him in pads the whole time”(disability staff). Sometimes residents were left in soiled pyjamas for periods of time. “... and they hadn’t even changed him, he’d had an accident and even when he came back from hospital, his pyjamas were all dirty” (family).

Predictable Routines. While acknowledging the difficulty of maintaining routines in hospital, predictability was described by carers as extremely important as most people with ID relied on routines and structured activities. Being left alone often led to strong reactions, resulting in behaviour that was distressing to everyone. “Most behaviour is quite manageable. Often you just need more structure, more consistency” (aged care staff).

Pain Management. Inability to treat pain effectively was a common concern expressed by carers. Several carers stated that pain would only be managed effectively if someone were present to ‘translate’ and insist that the pain be treated:

I looked at her and I said, "What's the matter love?" And she said “Oh, Denise it hurts, hurts”. So I went to the staff and I said to them, Eileen's in pain. Can you please make sure that she gets her morphineI came back from the meeting two hours later; she's had no pain control. ...And they said “Oh, but she hasn't complained”. (aged care staff)

Failure to identify pain also led to disruptive behaviour, compounding the distress for everyone.

Hospital Staff Communication

Descriptions of communication failures were pervasive. This was often attributed to lack of knowledge about the range of cognitive abilities in people with ID and a failure to assess the specific situation and respond accordingly. In some instances, diagnoses and treatment options were explained to people who lacked the capacity to understand:

She was really upset when I went in this particular afternoon; I said “What's the matter Betty?” And she said, “The doctor he talks over of the top of me and I don't understand and he wouldn't answer my questions”, so they'd had obviously a conversation about her ovarian cancer and modalities of treatment over the top of her. (aged care staff)

In other instances, hospital staff incorrectly assumed that a patient was unable to understand, failing to give them information that would have been helpful. “They don't understand that, just maybe, if we give this person the opportunity he will actually, he can understand us” (disability staff).

Communication was also affected by the limited time hospital staff had to interact with patients. This was particularly problematic for people with ID who had difficulty with speech. Carers noted the many misinterpretations of behaviour that expressed fears, desires or preferences:

They were complaining that Catherine was pushing them away, and I said: “Well that’s because she can’t tell you she doesn’t want to be hurt, or she doesn’t want the medication, she has to push away”, you know, didn’t seem to have registered with them at all. (family)

The concern of carers was magnified when people with ID were unable to ask for what they needed. Many residents with ID were unable to tell hospital staff when they needed something, whether it was for relief from pain, a trip to the toilet or simply to unwrap a sandwich. “Other times when she’s been in the hospital I’ve had grave misgivings about the amount of care that she’s had and just because she doesn’t call out, or know to push a button or anything...” (family). Misinterpreting inability to speak as not understanding was also noted by some carers:

... . so if you lack the power of speech, often you pick up straight away if someone is being a bit agitated with you ..., what we’d normally call in common parlance, pissed off they’ll pick it up straight away and pick up that agitation and it will feed into their behaviour ... and they get a bit pushy ... and before you know it they’ve thrown something or pushed the trolley over or tried to abscond. (disability staff)

Failing to heed carers’ advice often led to poor outcomes for residents. For example, a man with ID was brought from the group home to hospital with a badly infected neck. He had, over a long period of time, refused to have bandages on his skin. This information was imparted to nursing staff who applied the bandages as they would with any other patient, carefully instructing him not to touch them. The resident immediately removed the bandages:

I said: “He will pull it out, please, don’t do it”... “Oh no, no, no, I’ve got to do it, got to do it”, and she did it, and of course as she put the last bit of strapping across it, whoop, out it came,

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he just let go of my hand, which I had no hope of holding, and grabbed it and threw it across the room and back they came and wanted to bandage his neck. (family)

Carers frequently identified concerns about the lack of attention paid by hospital staff to their descriptions of residents' fears and phobias and warnings about residents' reactions to certain approaches. Explaining a catastrophic response from the resident, one family member said. "He's got a phobia of spaces and windows and that sort of thing". This background information was ignored, with the doctor refusing to move away from the window to examine him" (family).

Carers attributed many of the challenging behaviours exhibited by residents to the communication failures, lack of structure, and staff discomfort described above. Not understanding what was happening to them, being subjected to uncomfortable, frightening or painful treatments, and sensing someone's discomfort, led to fear, confusion and often disruptive behaviour. How these fears were managed had significant consequences for the resident and hospital staff. Explaining the source of behaviour that hospital staff found difficult, one family member said:

.. she doesn't like being there, because people hurt her there and she doesn't understand why they're doing it, and you can't explain it to her, she doesn't have any concept of it. She's only about two or three, intellectually. (family)

Early discharge

Many carers believed that disruptive behaviour resulted in early discharge:

... they end up being so distressed because none of that happens but the client ends up getting so distressed that either the hospital discharges them early or we end up having to send staff in to sit with that client which we're doing today because he's so distressed. (disability staff)

Carers believed, and were sometimes told, that the patient was being discharged early, that the group home was better equipped to provide the care. Formal discharge plans suggested that hospital staff had a misunderstanding about group homes and what they could provide. Contrary to

assumptions found in many discharge instructions, group homes did not have staff available during the day, and group home staff are not trained to manage illness or provide treatments. There were several reports of group home staff being pressured to take the resident home despite their inability to provide appropriate and 24-hour care. Refusal to accept a patient who needed ongoing care sometimes resulted in a referral to aged care. Group home staff often viewed this as a threat.

Carers described a general inability to gain the information from hospital staff they believed was necessary to care for the resident post discharge. Not knowing who to ask, not being able to find the right person, and convincing hospital staff to share information were all described as difficult. This was particularly compounded by confusion over who had authority to receive private information, the family or the group home staff. “You can never find anyone who knows anything and I’m not allowed to look at her file to find out information, it’s very difficult when the patient doesn’t speak” (family).

Positive Experiences and Systems that Worked

Contrary to the situations documented above, there were instances in which carers described very positive hospital experiences, and the time allotted for procedures had been extended to accommodate people with intellectual disability. The positive experiences all occurred in three hospitals that had clear policies, resources and systems in place to address the special needs of people with an ID. Several staff demonstrated an understanding of people with ID as they adapted the way they communicated with patients who were not verbal. “She (dental specialist) said if it is uncomfortable and it hurts put your hand up ... she was so patient” (family). One hospital, recognizing the fear related to unfamiliar places and procedures, arranged for the person with ID to be brought in the day before admission, taken around the hospital, introduced to people who would be involved in their care, and told what to expect. “We were well catered for (eye specialist) all the way through, everybody was very, very helpful from the anesthetist right through so we got on very well” (family). One hospital had an early discharge policy for people with ID. Partnering with post discharge carers, the hospital staff provided training, post discharge support and backup and home

visits, shortening the hospital stay while continuing oversight of the recovery. This allowed group home staff to cope effectively with the situation. One agency manager said, “And we’ve done some cross-training with the hospital staff in various things so that’s sort of helped” (family).

Strategies to Improve the Hospital Experience

In hospitals without clear policies or systems to support people with ID, carers developed strategies to minimize the stress of hospitalization. Some strategies were more successful than others. We detail four strategies in the following section.

Being Present.

Many carers spent as much time as possible in hospital in an effort to minimize distress to residents. Being present was intended to convey caring, provide emotional security, facilitate treatments and prevent premature discharge.

Well my husband and I watched her for the week, and there was somebody with her all the time. to get it done properly without any complications and things and it did work.
(family)

...it’s good for a client to have a staff member with them so that they are not so frightened and they’re with someone familiar (disability staff)

Being present was difficult for many family members who were older and frail and for siblings or nieces who had other commitments. However, despite the difficulties, family members often stayed for long stretches to assist with daily activities such as eating and toileting. “I made sure I was there during eating time because I wanted to help him” (family). Helping residents through medical procedures was also a reason to maintain a presence in hospital. This included calming the resident so that treatments and procedures could be completed or in some cases actually administering the treatment.

The nurse came and she tried to take blood from him and because he wriggled his hand, she said come here quick and help me. So I went around to help ... and I held him so she could do it. (family)

In responding to loss of daily routine, especially for residents who were well enough to be up, carers often stayed to keep the person engaged and prevent boredom. This was particularly important for people who tended to become disruptive on the ward or wander away.

Finally, being present allowed carers to explain procedures to residents, to assist hospital staff in making the environment less frightening, and to translate what residents were trying to communicate, minimizing fear, confusion and disruption. For the most part this was considered by carers as an effective strategy. Staff, particularly those who had known the resident for a long time, often assisted residents in hospital on a volunteer basis because there was no budget to cover the cost. They claimed they had become attached to the residents and felt that they could not leave them without support.

If a client needs to go to hospital and need staff with them that that's just a given. See I know that we will either, we will have to harass and do it on a volunteer basis which is, we've been here a long time with these men and I don't care about that [volunteering] and neither do the other staff ... (disability staff)

Information packages.

To prepare for the hospital stay, many carers developed 'communication aides' such as laminated sheets or even elaborate booklets. This was considered particularly important when the carer was unable to be present during the hospital stay. There was considerable consistency among these packages, often including descriptions of how residents communicated, what was likely to upset them, responses to stress or fear, ways to calm them, things they were unable to do for themselves. They also contained information about the person's usual medications:

We tell them how the person communicates, we tell them any ongoing health needs, we tell them you know their likes or dislikes. How they like to be toileted, how they eat, if they eat,

we've had a man with a peg feed go into hospital and the nurse tried to stuff a banana down his throat. (disability staff)

According to carers, hospital staff rarely showed any evidence of having read the materials, which increased carers' efforts to be present during the hospital stay and their distress at not being able to stay. "So they get that information, but then like you say if they don't follow it, if they don't read it, and they don't do it, it doesn't matter how good your information services are, if people don't read them...?" (aged care staff). In an attempt to call attention to the information, carers sometimes taped vital information to the wall or to the person's bed, assuming that everyone would see it, and read it. "We actually even did up a book that we hung on her bed which said, 'This is what I like to do, this is what I like, if this happens, this is what you can do to help me out'" (disability staff).

Carers described experiences that were distressing for the resident, carers and hospital staff that could have all been avoided if the hospital staff had read and used the information:

We told them ... you must not leave her dishes or cutlery on the table once she's finished, I even had something printed up and heat shrunk it into a clear envelope and taped it up over her bed and yet we were being rung and told this patient is uncooperative, throws her dishes and I said just lift your head six inches, read what's typed up in big letters and it warns you not to leave the bowls and so forth on her bedside table or trolley after she's finished.

(disability staff)

One of the difficulties with this strategy was that hospital staff were continually changing, so even if one staff member read the material, the next may not.

Partnering with hospital staff.

Many carers attempted to partner with hospital staff. Partnering required: listening and being listened to, solving problems together, using information provided by carers, responding sensitively to information about likes, dislikes, fears and idiosyncratic behaviour of the resident, and sharing important medical information. Sometimes partnering involved staff listening and responding to carer explanations about how to approach in a way that would not frighten the resident:

This gentleman needs to know what you're going to do because he thinks you're going to hurt him before you've even started. He needs that time and when they plastered him, they looked at me and she was, the poor girl was quite young and I said it's okay, he's not going to hurt you, but you need to give him the time. (disability staff)

Sometimes partnering meant that the carer, guided by the hospital staff, actually carried out a procedure:

The [eye doctor] was relying on me to get him to put his head up here, get him to do this, get him to do that, and like she had to put drops in his eyes first. ... She is saying, "Well you open his eyes and I will put the drops in". He is going, "No, no, no I want..." He calls me Chook. "Chook puts the drops in", he says. I said, "Okay Chook will put the drops in". (disability staff)

Partnering sometimes involved carers and hospital staff working together to prepare the resident for the hospital stay. For example, one group home manager described how hospital staff became actively involved in partnering prior to admission in order to minimize the resident's distress.

...we rang the hospital first of all and discussed the situation... ... so we organized for ... him to come over and visit and he was pretty anxious and apprehensive about that... We wandered through the ward, explained what was going to happen. (disability staff)

Sometimes family or other carers were asked by hospital staff to come into the hospital to help with the care of the resident: "They ring and say will you come and sit with him?" The intention and ability of staff involved in the care of the residents to share information and to cooperate with and respect each other's skills and knowledge was seen as essential for the reduction in stress of a resident during a hospital stay. Partnering required both giving and receiving information.

A most important component of partnering was actually participating in decision making. Being given information without being involved in decision making was not seen as sufficient by most carers. Several shared their distress over not being involved in decisions about the resident, about discharge, treatment and ways of dealing with residents' fears and idiosyncratic behaviour.

Being notified in advance about decisions that would be made, explaining the situation in language that could be understood, and allowing carers to participate in problem solving were all important, but rare. The most negative experiences were those in which decisions were made entirely by hospital staff, and carers as well as residents were expected to just go along, no matter how inappropriate they believed the decision to be. In these instances, carers often felt powerless to resist what they saw as intimidation by powerful figures. Carers felt that at times they were 'rail-roaded' by hospital staff to agree to something they did not think was in the best interests of the resident.

Advocating.

Some carers took on an advocacy role. One common issue requiring advocacy is timing and post hospital location, particularly preventing premature discharges and moves to aged care. There were instances where group home staff in particular, stood up to hospital staff insisting that a discharge decision be changed. "... we ended up threatening each other she stated that she was going to put Danielle in an ambulance and drop her off and I stated to her well we're not going to accept her and if you do that I'll call the police" (disability staff).

Advocating was only partially successful. It was not undertaken lightly because family members as well as group home staff, were reluctant to take on this role because they said they were intimidated by the medical profession and/or felt that their level of knowledge was inadequate and they were sometimes unsure of their legal standing. All serious attempts were only described by staff.

Impact of Ageing Family Systems on Strategies

Because parents and siblings were elderly, staying for long periods of time, especially over night, was exhausting and debilitating. Siblings often had work and family commitments, lived some distance away, and often had chronic illnesses. Despite this, many family members tried to stay with their disabled relative as much as possible.

When there was more than one family member or group home staff involved, they often took shifts. “Staff initially goes with him and then I go in and take over. I stay right through until he’s out of the hospital ... if he’s in there for a length of time” (family). When family members were unable to stay, group home staff often volunteered personal time to stay with the resident. As hospital stays became extended, however, it became increasingly difficult for staff to do this. Group home sometimes rostered staff to stay with the resident in hospital. “Generally ... our staff stay with them the whole time but if they’re actually admitted into hospital for any length of time, we actually roster staff on to go and sit with them for a couple of hours every day” (disability staff).

Rostering staff to stay for extended times required group homes to find additional staff, creating financial stress for the agency. Well as long as it’s short term it’s [funding] not a problem. We just manage to, oh well, you know, they’re in hospital, can someone go and spend a couple of hours or something like that, we do” (disability staff).

Conclusion

This study confirms the findings of several previously reported studies documenting staff and family distress about to poor support and treatment people with intellectual disability receive in the hospital system (Gibbs, Brown & Muir, 2008; ; Iacono, & Davis, 2003; Lennox, Diggins & Ugoni, 2000; Mencap, 2004; O’Hara, 2006; Wallace & Beange, 2008). It adds insights into the strategies carers use in their efforts to improve the hospital experiences for people with intellectual disability, documenting 1) strategies used in anticipation of a hospital stay (when the hospital stay is planned), 2) how carers attempt to influence the care, 3) the evidence that carers use to assess the quality of care, including whether the hospital staff has heeded the advice of the carer, and 4) the consequences of using those strategies for the patient, the family member, and the group home staff. Although not explored in depth, the study also provides insights into the impact of systems that deliberately take account of patients with an intellectual disability.

The study reported here adds to that literature by providing insights into the hospital experience of residents in group homes and the issues that arise as carers attempt to mediate their

care, in a situation where the family system is ageing and residents are increasingly reliant on group home staff for primary support. While past research has documented, the vigilance by parents of hospitalized children, and their need for continual presence, this study has examined the experiences of carers of ageing people with intellectual disability. While constant vigilance and participation in hospital care is stressful even for young parents, aged parents face additional challenges related to their own health issues. Siblings were generally unable to substitute adequately for the absence of parent carers as they often lived at some distance from the group and/or the hospital, had conflicting commitments and were often less connected to the resident than parents. Finally, relying on low wage group home staff to volunteer their personal time to stay with residents in hospital raises serious ethical questions and seems untenable as a system of care. Hiring group home staff to stay with residents in hospital strains the budgets of group homes, and will become increasingly difficult as more residents age.

Although only a small subset of hospitals had implemented programs specifically to accommodate people with intellectual disability, this study suggests that such systems are possible and effective. In particular, the efforts to reduce fear and the responses to fear and the deliberate early discharge that was effectively supported by the hospital seems to have some potential for group home residents. This would involve a rethinking of the role of group homes and the skills of group home staff as well as clearer and more effective articulation between the ageing and disability sectors, as others have suggested (Putnam, 2009).

In an Australian policy context where social inclusion is high on the agenda and one of the aims of the 2002- 2012 Victorian State Disability Plan was to take the lead in improving the accessibility and responsiveness of public services, this study draws further attention to the failure of the hospital system to adapt and accommodate to the needs of people with intellectual disabilities (Department of Human Services, 2002). It suggests the need for specific government initiatives to address this issue and highlights the need to carefully study the programs currently in place to support hospitalized people with intellectual disability, learning from what works and what needs to

be done differently. It also indicates the need for further research on post hospital care of group home residents and the long term impact of having (and not having) hospital systems designed to support people ageing with an intellectual disability. Finally, the study has identified some of the challenges faced when multiple carers are involved and the authority to make decisions is not clearly vested in any individual. There is need for both research and policy development to address the complexity of decision making under such circumstances.

References

Australian Institute of Health and Welfare (AIHW) (2008). *Australia's health: The eleventh biennial health report of the Australian Institute of Health and Welfare* (cat.no. AUS65.). Canberra: AIHW.
<http://www.aihw.gov.au/publications/aus/ah08/ah08.pdf>

Auditor General of Victoria (2008). *Accommodation for people with a disability*. Melbourne: Victorian Government.

Backer, C., Chapman, M., & Mitchell, D. (2009). Access to secondary healthcare for people with intellectual disabilities: A review of the literature. *Journal of Applied Research in Intellectual Disabilities*, 22, 514-525.

Beange, H., McElduff, A., & Baker, W. (1995). Medical disorders of adults with mental retardation: a population study. *American Journal of Mental Retardation*, 99, 595-604.

Bigby, C. (in press). A five country comparative review of accommodation support policies for older people with intellectual disability. *Journal of Policy and Practice in Intellectual Disability*.

Bowers, B., & Schatzman, L. (2009). Dimensional analysis. In J. M. Morse, P. N. Stern, J. Corbin, B. Bowers, K. Charmaz & A. Clarke (Eds.), *Developing grounded theory: The second generation* (pp. 86-126). Walnut Creek, CA: Left Coast Press.

Bowers, B., Bigby, C., & Webber, R. (2009). Intellectual disability and ageing. In R. Nay & S. Garratt (Eds.), *Interdisciplinary Care of Older People: Issues and Innovations* (pp. 60-77). Sydney: Elsevier.

Brown, A., & Gill, C. (2002). Women with developmental disabilities: health and aging. *Current Women's Health Reports*, 2, 219-225.

Caron, C. D., & Bowers, B. J. (2000). Methods and application of dimensional analysis: A contribution to concept and knowledge development in nursing. In B. L. Rodgers & K. A. Knafl (Eds.), *Concept*

development in nursing: *Foundations, techniques and applications* (2nd ed., pp. 285-320). Philadelphia: Saunders.

Connolly, B. (2001). Aging in individuals with lifelong disabilities. *Physical & Occupational Therapy in Paediatrics*, 21(4), 23-47.

Department of Human Services. (2002). State Disability Plan. Melbourne: Department of Human Services.

Department of Human Services (2009). Shared Supported Accommodation Program. Accessed from http://www.DHM.vic.gov.au/disability/supports_for_people/accommodation/shared_supported_accommodation on 20 October 2009.

Dewar, B., Tocher, R., & Watson, W. (2003). Enhancing partnerships with relatives in care settings. [Miscellaneous Article]. *Nursing Standard*, 17(40), 33-39.

Durvasula, S., & Beange, H. (2001). Health inequities in people with intellectual disability: Strategies for improvement. *Health Promotion Journal of Australia*, 11(1), 22-31.

Emerson, E., Hatton, C., Felce, D., & Murphy, G. (2001). *Learning disabilities: The fundamental facts*. London: The Foundation for People with Learning Disabilities

Fisher, K., & Kettl, P. (2005). Aging with Mental Retardation: Increasing population of older adults with MR require health interventions and prevention strategies. *Geriatrics*, 60(4), 26-29.

Forbes, S. (1999). National and state policy. In Reframing opportunities for people with an intellectual disability. In E. Ozanne, C. Bigby, S. Forbes, C. Glennen, M. Gordon & C. Fyffe (Eds.), (pp. 63 -128). Melbourne: School of Social Work, University of Melbourne.

Gibbs, S. M., Brown, M. J., & Muir, W. J. (2008). The experiences of adults with intellectual disabilities and their carers in general hospitals: a focus group study. [in press]. *Journal of Intellectual Disability Research*, 52(12), 1061-1077.

Glaser, B. (1967) Theoretical Sensitivity. Sociology Press, Mill Valley, California

Hemsley, B., Balandin, S., & Togher, L. (2008). Professionals' views on the roles and needs of family carers of adults with cerebral palsy and complex communication needs in hospital. *Journal of Intellectual & Developmental Disability*, 33(2), 127 - 136.

Horwitz, S., Kerker, B., Owens, P., & Zigler, E. (2000). *The Health Status and Needs of Individuals with Mental Retardation*. New Haven CT: Yale University Press.

- Iacono, T., & Davis, R. (2003). The experiences of people with developmental disability in emergency departments and hospital wards. *Research in Developmental Disabilities, 24*, 247-264.
- Janicki, M., Dalton, A., Henderson, M., & Davidson, P. (1999). Mortality and morbidity among older adults with intellectual disability: health services considerations. *Disability and Rehabilitation, 21*(5), 284-294.
- Lennox, N., Diggins, J., & Ugoni, A. (2000). Health care for people with an intellectual disability: general practitioners' attitudes, and provision of care. *Journal of Intellectual & Developmental Disability, 25*(2), 127-133.
- MENCAP. (1998). *The NHS - health for all?* London: MENCAP.
- MENCAP. (2004). *Treat me right! Better healthcare for people with a learning disability*. London: MENCAP.
- Morse, J. M., Stern, P. N., Corbin, J., Bowers, B., Charmaz, K., & Clarke, A. (Eds.). (2009). *Developing grounded theory: The second generation*. Walnut Creek: CA: Left Coast Press.
- O'Hara, D. (2008). Invited commentary on Wallace and Beange (2008): "On the need for a specialist service within the generic hospital setting". *Journal of Intellectual and Developmental Disability, 33*(4), 362-364.
- Ouellette-Kuntz, H., Gardin, N., Lewis, M., Minnes, P., Martin, C., & Holden, J. (2005). Addressing Health Disparities through Promoting Equity for Individuals with Intellectual Disability. *Canadian Journal of Public Health, 96*, S8-S22.
- Strauss, A. L. (1987). *Qualitative analysis for social scientists*. Cambridge, UK: Cambridge University Press.
- Wallace, R. A., & Beange, H. (2008). On the need for a specialist service within the generic hospital setting for the adult patient with intellectual disability and physical health problems. *Journal of Intellectual and Developmental Disability, 33*(4), 354-361.
- Walsh, K., Kastner, T., & Croscopme, T. (1997). Characteristics of hospitalizations for people with developmental disabilities: utilization, costs and impact of care coordination. *American Journal of Mental Retardation, 101*, 505-520.
- Walsh, P., Heller, T., Schupf, N., & van Schrojenstein, H. (2001). Healthy ageing - adults with intellectual disabilities: women's health and related issues. *Journal of Applied Research in Intellectual Disabilities, 14*, 195-217.
- Yang, Q., Rasmussen, S., & Friedman, J. (2002). Mortality associated with Down's syndrome in the USA from 1983 to 1997: a population based study. *The Lancet, 359*(9311), 1019.